

ACT 204

H.B. NO. 2109

A Bill for an Act Relating to Health.

Be It Enacted by the Legislature of the State of Hawaii:

SECTION 1. The legislature finds that while fetal alcohol exposure is one of the leading known causes of mental retardation in industrialized nations, the majority of those exposed are not mentally retarded. Individuals with diagnosed or undiagnosed fetal alcohol exposure suffer substantially from secondary disabilities, such as child abuse and neglect, separation from families, multiple foster placements, school failure, juvenile detention, job instability, depression, aggression, and other serious mental disorders. These secondary disabilities come at a high cost to the individuals, their families, and society. The legislature finds that these problems can be reduced substantially by early diagnosis and appropriate, effective intervention.

Fetal alcohol spectrum disorder (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother consumed alcohol during pregnancy. These effects may include physical, mental, behavioral, and learning disabilities with possible lifelong implications.

Nationwide, the incidence of FASD is estimated to be ten per one thousand live births. Nationally, more children are born each year with FASD than those born with spina bifida, multiple sclerosis, Down Syndrome, and HIV combined. There are an estimated one hundred seventy-five children born each year in Hawaii with FASD. Human costs of prenatal alcohol exposure are great, as are the economic costs. Caring for someone with FASD may cost as much as \$5,000,000. Nationally, as many as forty thousand babies are born each year with FASD, costing the United States about \$4,000,000,000.

FASD is the most underdiagnosed developmental disability, both in Hawaii and across the United States. The effect of prenatal alcohol exposure lasts a lifetime, yet FASD is totally preventable. The effects of the known risk factors may be ameliorated with early intervention and through effective systems of care and services.

Most persons with FASD are undiagnosed or misdiagnosed and frequently do not follow treatment plans, even when properly diagnosed. Persons with FASD frequently fail in traditional treatment and other service systems and are commonly identified as being noncompliant, uncooperative, and unmotivated in all systems of services and care.

There are currently few FASD-specific services in Hawaii, and only eighty-nine cases of FASD have been documented and reported to Hawaii's birth defects registry from 1966 to 2002. Department of health data from 2002 indicated that forty per cent of pregnant women surveyed consumed alcohol prior to becoming pregnant, and almost four per cent indicated that they consumed alcohol during pregnancy, which put their infants at risk for FASD.

Information from a 2003 department of health behavioral risk prevalence survey shows that almost eighty-two per cent of the women surveyed consumed alcohol one month prior to the survey, and almost four per cent indicated that they engage in binge drinking. Because FASD can occur in any community where women consume alcohol during pregnancy, it is a statewide public health concern that has service, policy, and economic implications for virtually all state departments.

Because FASD is underdiagnosed and families as well as providers have significant problems in addressing the multiple, challenging needs of persons with this disorder, fourteen states already have state FASD coordinators. These FASD coordinators serve as a key educational, informational, and coordination link between departments and agencies dealing with persons with FASD.

Poor coordination hampers prevention, diagnosis, and service delivery. A state FASD coordinator would organize all fetal alcohol syndrome activities and would ensure that a comprehensive state strategic plan to address FASD is drafted and implemented.

The purpose of this Act is to coordinate and develop FASD information, education, policies, and support services statewide by establishing a state FASD coordinator position within the department of health's family health services division.

SECTION 2. There is established within the family health services division of the department of health one full-time equivalent permanent professional fetal alcohol spectrum disorder coordinator position. The fetal alcohol spectrum disorder coordinator shall act as a public point of contact for individuals and families affected by fetal alcohol spectrum disorder and shall help to coordinate a statewide system of services for persons with fetal alcohol spectrum disorder by:

- (1) Increasing statewide awareness of fetal alcohol spectrum disorder both in the general public and in at-risk populations;
- (2) Expanding statewide capacity to identify and intervene with at-risk pregnant and parenting women;
- (3) Advocating, mobilizing, and coordinating state and community resources to assist persons and families affected by fetal alcohol spectrum disorder to receive the support they need;
- (4) Improving statewide service delivery to individuals and families affected by fetal alcohol spectrum disorder;
- (5) Coordinating a statewide strategic plan to address the full range of cradle-to-grave fetal alcohol spectrum disorder care, treatment, education, and prevention issues;
- (6) Facilitating and coordinating state fetal alcohol spectrum disorder task force meetings; and
- (7) Facilitating development and implementation of a comprehensive, statewide system of care for the prevention, identification, surveillance, and treatment of fetal alcohol spectrum disorders.

SECTION 3. There is appropriated out of the general revenues of the State of Hawaii the sum of \$100,000 or so much thereof as may be necessary for fiscal year 2006-2007 for operating expenses and to establish a full-time equivalent permanent professional fetal alcohol spectrum disorder coordinator position in the family health services division of the department of health.

The sum appropriated shall be expended by the department of health for the purposes of this Act.

SECTION 4. This Act shall take effect on July 1, 2006.

(Approved June 19, 2006.)